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The Patient Perspective:

Unmet Treatment Needs in Adults With Attention-Deficit/Hyperactivity Disorder

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ABSTRACT

Objective: To characterize impairments in daily life experienced by pharmacologically treated adults with attention-deficit/hyperactivity disorder (ADHD) versus adults without ADHD and to identify unmet needs in ADHD treatment from the perspective of adults with ADHD.

Methods: Adults with ADHD taking prescription medication for ≥ 6 months and adults without ADHD agreed to participate in a cross-sectional online survey during December 2016. Participants with ADHD were stratified by their current ADHD medication: long-acting (LA) once daily, short-acting (SA) ≤ 2 times/d, and augmenters (AU; LA > 1 time/d, SA > 2 times/d, or LA plus SA).

Results: A total of 616 adults with ADHD (SA: n = 166, LA: n = 201, AU: n = 249) and 200 adults without ADHD completed the survey. Even with treatment, adults with ADHD reported substantial impairments in their everyday life, particularly at home, at school/work, and in their social life and relationships. Participants with ADHD experienced impairments throughout the day, especially in the afternoon and evening. Signs or symptoms were reported when the ADHD medication was wearing off, resulting in negative effects (including school work, homework, work responsibilities, household responsibilities, emotional responses, mood, and relationships) on the daily life of adults with ADHD.

Conclusions: Adults with ADHD, despite receiving medication, experienced impairments and challenges in many aspects of their daily life. Adults with ADHD described various unmet needs, especially those relating to the duration of treatment effect. When optimizing treatment for adults with ADHD, it is important that the treatment regimen is sufficient to meet the needs of the patient throughout the day.

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Attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental disorder, with impairments persisting into adulthood in some patients.¹⁻³ Adult ADHD imposes a substantial burden,^{4,5} affecting many areas of the individual's life.^{6,7} According to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*, ADHD is distinguished by a persistent pattern of inattention, hyperactivity, and/or impulsivity that interferes with functioning in ≥ 2 settings.⁸ Therefore, for clinicians to diagnose and determine ADHD severity in adults, it is imperative to confirm functional impairments. Consistent with the importance of functional impairment for ADHD diagnosis, outcome studies⁹⁻¹⁴ indicate that adults with ADHD report more work, school, and social life impairments than matched controls without ADHD.

Consideration of functional impairments is critical not only for diagnosing ADHD but also for ADHD treatment and management. Management options for adult ADHD include pharmacologic and psychosocial interventions.^{15,16} Although psychosocial therapy is considered an essential component of ADHD treatment,¹⁷ pharmacotherapy is a mainstay of treatment for adult ADHD. There are many short-acting (SA) and long-acting (LA) formulations of stimulants and nonstimulants approved for treating adult ADHD.¹⁸ Despite these pharmacologic options, some patients continue to experience symptoms and functional impairments.¹⁹⁻²² However, the degree and type of impairments experienced in daily life by adults with ADHD undergoing treatment are not well characterized.

Studies in other therapeutic areas indicate that differences in perception exist between patients and clinicians regarding patient symptoms and impairments,²³⁻²⁸ highlighting the importance of collecting information directly from the patient. Outside of the clinical trial setting, there is a relative lack of patient-reported burden of ADHD in adults. The objectives of this study were to characterize the type and degree of daily life impairments in adults with ADHD receiving pharmacotherapy versus adults without ADHD and to identify unmet needs in ADHD treatment from the perspective of adults with ADHD. Examination of the relative impact of ADHD in those who were medicated versus not medicated was not a goal of this study. Therefore, a nonmedicated ADHD group was not included in the study.

METHODS

This cross-sectional online survey, which was conducted in December 2016, included adults diagnosed with ADHD currently taking prescription ADHD medications and adults without

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Clinical Points

- Adults with attention-deficit/hyperactivity disorder (ADHD) who were taking prescription ADHD medication for at least 6 months reported substantial impairment across multiple aspects of their everyday life compared with adults not diagnosed with ADHD, despite reporting benefits from their medication.
- Adults with ADHD who were taking prescription ADHD medication for at least 6 months experienced impairment throughout the day, especially in the afternoon and evening, despite reporting benefits from their medication.
- When optimizing treatment for adults with ADHD, it is important that the treatment regimen be sufficient to meet the needs of the patient throughout the day and into the evening.

ADHD. Adults with ADHD were stratified by treatment (SA: participants taking an SA medication ≤ 2 times/d; LA: participants taking a once-daily LA medication; augmenters [AU]: participants augmenting their current ADHD treatment by taking an SA medication > 2 times/d, an LA medication > 1 time/d, or an SA plus LA medication). The study was reviewed and approved by a central institutional review board (Salus IRB, Austin, Texas) and performed in accordance with the ethical standards of the Declaration of Helsinki.²⁹ All participants provided informed consent before initiating the survey. Each participant received the equivalent of \$3 in panel points.

Survey Development

The survey was developed using a patient blog-forum analysis, a targeted literature search, interviews with clinical experts ($n=2$) who were psychiatrists specializing in adult ADHD, and 1-on-1 qualitative interviews with adults with ADHD ($n=31$). Qualitative interviews were conducted to understand the symptoms and life challenges associated with ADHD. Participants were interviewed by trained interviewers using a semistructured guide to gather information regarding participants' experiences with ADHD, focusing on identifying burden and unmet needs. Survey items for the study were generated using the qualitative interview data.

The draft survey was tested on a small sample of adults with ADHD ($n=5$) using cognitive interviewing methodology. Online survey content was finalized based on this feedback.

Online Survey

Participants with ADHD completed the 30-minute survey (Appendix A: Burden Survey for ADHD Population). Survey questions examined participants' experiences with ADHD treatment and their everyday activities in multiple areas (work/school, home, and social life/interpersonal relationships). Participants with ADHD also completed questions related to clinical history, diagnosis, and experience with ADHD and ADHD treatment history. Non-ADHD

participants completed a 15-minute version of the survey (Appendix B: Burden Survey for Normative Population) that included questions related to everyday activities and sociodemographic characteristics.

Participant Selection

Participants were recruited in the United States through research participant panels, from which those interested in participating in research received invitations for studies or surveys. The recruitment goal was 600 adults with ADHD (200/subgroup) and approximately 200 adults without ADHD.

Participants with ADHD were eligible if the following criteria were met at screening: patient-reported ADHD diagnosis; ≥ 18 years old; currently taking ≥ 1 prescription ADHD medication (either a stimulant or a nonstimulant), with treatment initiated ≥ 6 months before screening; no patient-reported diagnosis of a mental health disorder that would affect the ability to complete the survey (eg, dementia, schizophrenia); adequate written and oral fluency in English; Internet access; willing to provide informed consent; and able to comply with study procedures. The same criteria were used for non-ADHD participants, with the exceptions that non-ADHD participants did not have an ADHD diagnosis and could not be taking ADHD medication.

Statistical Analyses

Descriptive statistics were calculated for all questions. Mean \pm SD or standard error (SE) is reported for continuous data. Percentages are reported for categorical data. Inferential analyses of sociodemographic and clinical characteristics consisted of χ^2 tests for categorical variables and analysis of variance (ANOVA) for continuous variables. χ^2 tests were also used to assess challenges in daily life, challenging parts of the day, and the effects of medication wearing off. Satisfaction with medication was assessed using ANOVA, with post hoc Tukey tests. Statistical significance was set at $P < .05$.

Sample size calculations were not performed. A standardized sample of 200 participants per group, with a total sample of 600 participants, was considered large enough for statistical comparisons while minimizing the constraints of large sample acquisition.

RESULTS

Participant Characteristics

The survey was completed by 616 adults with ADHD (SA: $n=166$, LA: $n=201$, AU: $n=249$) and 200 adults without ADHD. Demographic and clinical characteristics are reported in Table 1. Most participants were female. Participants with ADHD were significantly younger than non-ADHD participants ($P=.0003$). Significantly greater percentages of ADHD participants than non-ADHD participants were white ($P=.0386$) and reported higher education levels ($P < .0001$), being employed ($P < .0001$), attending school/classes ($P=.0017$), and having more comorbidities ($P < .0001$). The mean number of children per

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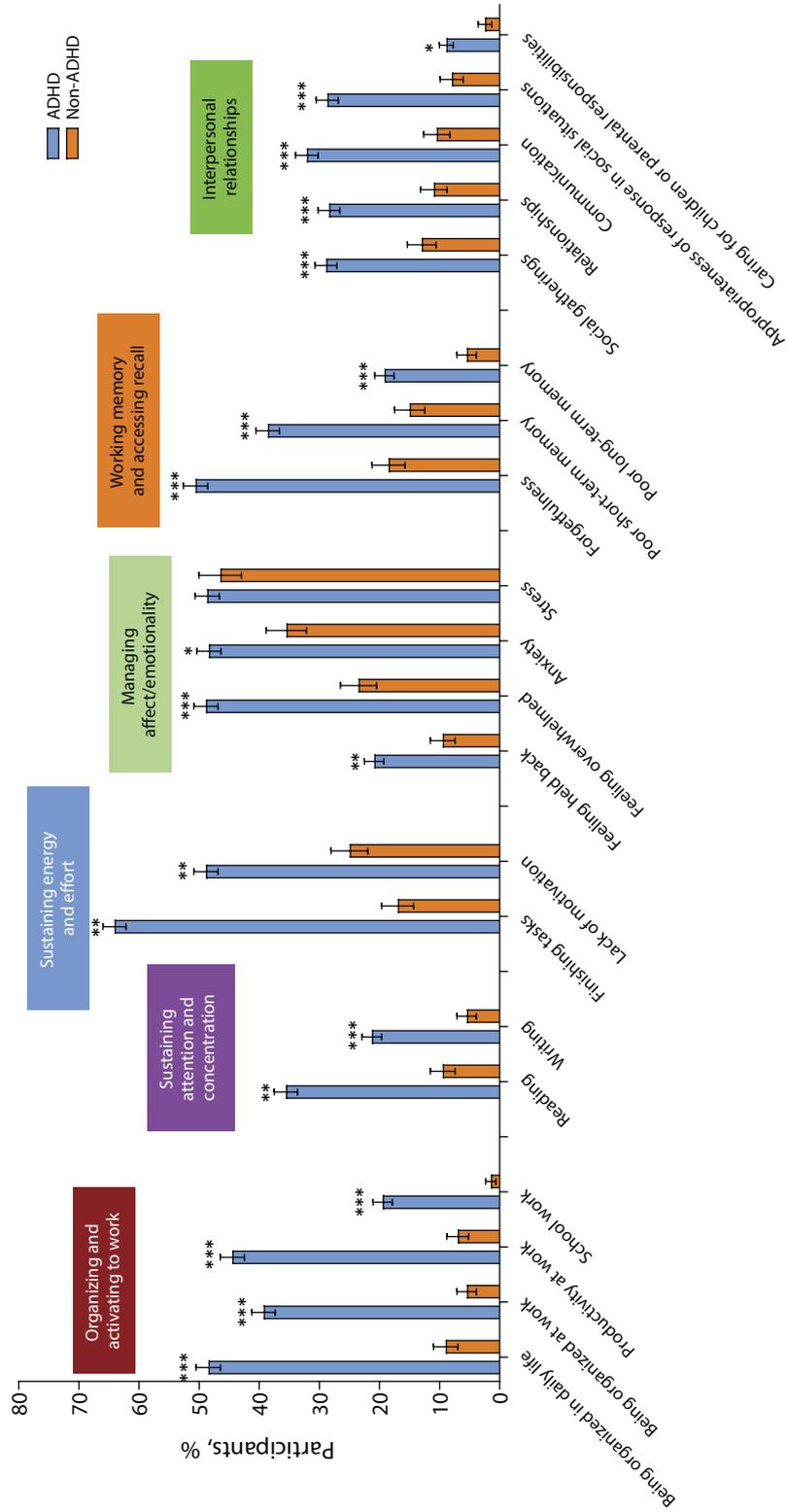
Table 1. Sociodemographic and Clinical Characteristics

Characteristic	Non-ADHD (N=200)	ADHD Subgroups				P Value ^a
		All (N=616)	SA (n=166)	LA (n=201)	AU (n=249)	
Age, y						
Mean (SD)	43.1 (17.0)	39.0 (12.4)	38.8 (13.2)	40.0 (13.3)	38.5 (11.1)	.0003
Median	38	36.5	36	38	36	.0339
Range	18–84	18–74	19–70	18–74	18–67	
Sex, n (%)						
Male	60 (30.0)	183 (29.7)	44 (26.5)	52 (25.9)	87 (34.9)	.9374 ^b
Female	140 (70.0)	433 (70.3)	122 (73.5)	149 (74.1)	162 (65.1)	
Racial background, n (%)						
White	168 (84.0)	551 (89.4)	154 (92.8)	183 (91.0)	214 (85.9)	.0386 ^b
Other	32 (16.0)	65 (10.6)	12 (7.2)	18 (9.0)	35 (14.1)	
Highest level of education completed, n (%)						
Less than high school	10 (5.0)	3 (0.5)	0	2 (1.0)	1 (0.4)	<.0001 ^b
High school/GED	38 (19.0)	53 (8.6)	15 (9.0)	15 (7.5)	23 (9.2)	
Some college, no degree	39 (19.5)	115 (18.7)	35 (21.1)	42 (20.9)	38 (15.3)	
Associate degree	12 (6.0)	77 (12.5)	25 (15.1)	25 (12.4)	27 (10.8)	
Trade school	5 (2.5)	26 (4.2)	6 (3.6)	4 (2.0)	16 (6.4)	
Undergraduate degree	64 (32.0)	214 (34.7)	55 (33.1)	74 (36.8)	85 (34.1)	
Postgraduate degree	32 (16.0)	128 (20.8)	30 (18.1)	39 (19.4)	59 (23.7)	
Relationship status, n (%)						
Married	98 (49.0)	277 (45.0)	67 (40.4)	98 (48.8)	112 (45.0)	.0176 ^b
Separated	1 (0.5)	14 (2.3)	4 (2.4)	2 (1.0)	8 (3.2)	
Divorced	22 (11.0)	64 (10.4)	18 (10.8)	23 (11.4)	23 (9.2)	
Widowed	8 (4.0)	5 (0.8)	2 (1.2)	2 (1.0)	1 (0.4)	
Living with partner	16 (8.0)	61 (9.9)	21 (12.7)	13 (6.5)	27 (10.8)	
In a serious relationship	11 (5.5)	62 (10.1)	16 (9.6)	21 (10.4)	25 (10.0)	
Single, not in a serious relationship	43 (21.5)	129 (20.9)	38 (22.9)	42 (20.9)	49 (19.7)	
Other	1 (0.5)	4 (0.6)	0	0	4 (1.6)	
Total other people in household						
Mean (SD)	1.9 (1.5)	2.0 (1.6)	2.0 (1.6)	1.9 (1.5)	2.2 (1.7)	.2267
Median	1	2	2	1	2	.3000
Total children cared for in household						
Mean (SD)	0.7 (1.0)	1.0 (1.2)	1.0 (1.2)	0.8 (1.1)	1.1 (1.2)	.0084
Median	0	0	1	0	1	.0058
Employment status, n (%)						
Employed, full-time	84 (42.0)	349 (56.7)	96 (57.8)	107 (53.2)	146 (58.6)	<.0001 ^b
Employed, part-time	19 (9.5)	66 (10.7)	17 (10.2)	20 (10.0)	29 (11.6)	
Self-employed	12 (6.0)	37 (6.0)	13 (7.8)	7 (3.5)	17 (6.8)	
Student	23 (11.5)	32 (5.2)	8 (4.8)	12 (6.0)	12 (4.8)	
Stay-at-home parent/homemaker	17 (8.5)	33 (5.4)	2 (1.2)	18 (9.0)	13 (5.2)	
Unemployed	35 (17.5)	24 (3.9)	6 (3.6)	14 (7.0)	4 (1.6)	
Retired	7 (3.5)	27 (4.4)	9 (5.4)	12 (6.0)	6 (2.4)	
Disabled	3 (1.5)	48 (7.8)	15 (9.0)	11 (5.5)	22 (8.8)	
Currently attending school, n (%)						
Yes	22 (11.0)	129 (20.9)	35 (21.1)	36 (17.9)	58 (23.3)	.0017 ^b
No	178 (89.0)	487 (79.1)	131 (78.9)	165 (82.1)	191 (76.7)	
Self-reported current general health, n (%)						
Excellent	25 (12.5)	70 (11.4)	23 (13.9)	20 (10.0)	27 (10.8)	.1025 ^b
Very good	76 (38.0)	219 (35.6)	59 (35.5)	76 (37.8)	84 (33.7)	
Good	60 (30.0)	239 (38.8)	64 (38.6)	72 (35.8)	103 (41.4)	
Fair	35 (17.5)	72 (11.7)	16 (9.6)	28 (13.9)	28 (11.2)	
Poor	4 (2.0)	16 (2.6)	4 (2.4)	5 (2.5)	7 (2.8)	
Number of mental health–related comorbidities, n (%)						
None	149 (74.5)	209 (33.9)	60 (36.1)	73 (36.3)	76 (30.5)	<.0001 ^b
1	27 (13.5)	159 (25.8)	44 (26.5)	42 (20.9)	73 (29.3)	
2	17 (8.5)	138 (22.4)	37 (22.3)	50 (24.9)	51 (20.5)	
≥3	7 (3.5)	110 (17.9)	25 (15.1)	36 (17.9)	49 (19.7)	
Self-reported ADHD severity, n (%)						
Very mild	NA	28 (4.5)	4 (2.4)	4 (2.0)	20 (8.0)	NA
Mild	NA	94 (15.3)	27 (16.3)	29 (14.4)	38 (15.3)	
Moderate	NA	338 (54.9)	94 (56.6)	126 (62.7)	118 (47.4)	
Severe	NA	128 (20.8)	33 (19.9)	35 (17.4)	60 (24.1)	
Very severe	NA	28 (4.5)	8 (4.8)	7 (3.5)	13 (5.2)	
Age at diagnosis, y ^c						
Mean (SD)	NA	28.1 (14.5)	29.2 (15.3)	28.5 (15.4)	27.2 (13.0)	NA
Median	NA	28	27	29	28	
Range	NA	4–69	4–62	4–69	4–60	
Overview of medication classes used						
Amphetamines						
SA	NA	269 (43.7)	NA	121 (60.2)	148 (59.4)	NA
LA	NA	95 (15.4)	23 (13.9)	NA	72 (28.9)	NA
Methylphenidate						
SA	NA	128 (20.8)	NA	42 (20.9)	86 (34.5)	NA
LA	NA	24 (3.9)	0 (0)	NA	24 (9.6)	NA
Nonstimulants						
SA	NA	60 (9.7)	NA	24 (11.9)	36 (14.5)	NA
LA	NA	24 (3.9)	6 (3.6)	14 (7.0)	4 (1.6)	NA

^aAll ADHD groups combined vs the non-ADHD group; χ^2 tests were used to assess categorical variables, and analyses of variance were used to assess continuously distributed data. ^bBased on nonparametric (χ^2) test. ^cParticipants reporting an age of diagnosis from 0 to 3 years were considered as missing data. Abbreviations: ADHD = attention-deficit/hyperactivity disorder, AU = augmenter medication group, GED = General Educational Development, LA = long-acting medication group, NA = not applicable, SA = short-acting medication group.

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Figure 1. Difference in Proportion of Patients With ADHD Versus Without ADHD Who Reported Overall Effects/Challenges in Aspects of Daily Life^{a,b}



^aError bars represent the standard error.
^bBased on χ^2 tests (* $P < .05$, ** $P < .001$, *** $P < .0001$) vs the non-ADHD group.
 Abbreviation: ADHD=attention-deficit/hyperactivity disorder.

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household was significantly higher in ADHD compared with non-ADHD participants ($P = .0084$).

Across ADHD subgroups, ADHD symptom severity was significantly different ($P = .0122$). The AU subgroup was less likely to report having moderate ADHD and more likely to report having mild, severe, or very severe ADHD than the LA subgroup ($P = .0036$). Stimulants were used more frequently than nonstimulants, and SA formulations were used more frequently than LA formulations. Further, amphetamine-based stimulants were used more frequently than methylphenidate-based stimulants.

Impairment: ADHD Versus Non-ADHD

Everyday life. Significantly greater percentages of ADHD participants compared with non-ADHD participants reported impairment in organizing and activating to work, sustaining attention and concentration, sustaining energy and effort, managing affect/emotionality, working memory and accessing recall, and dealing with interpersonal relationships (Figure 1).

Home. Significantly greater percentages of ADHD than non-ADHD participants reported difficulties in sustaining attention and concentration (completing a task: 58.6% vs 15.5%, $P < .0001$), organizing/activating to work (paying bills on time: 28.4% vs 12.0%, $P < .0001$; keeping the household organized: 52.8% vs 19.0%, $P < .0001$; managing household chores: 48.1% vs 19.0%, $P < .0001$), sustaining energy and effort (caring for pets: 11.0% vs 5.0%, $P = .0116$), and dealing with interpersonal relationships (caring for children or handling parental responsibilities: 11.7% vs 3.0%, $P = .0003$).

Social life. Significantly greater percentages of ADHD than non-ADHD participants reported impairment in sustaining attention and concentration (difficulty focusing when with friends/family: 29.2% vs 6.0%, $P < .0001$; difficulty holding conversations: 31.7% vs 10.0%, $P < .0001$), organizing and activating to work (late to social events: 26.3% vs 6.5%, $P < .0001$), sustaining effort (not able to sit through a movie: 19.0% vs 7.0%, $P < .0001$), accessing working memory and recall (tended to forget names: 37.5% vs 23.0%, $P = .0002$; forget to call friends: 29.9% vs 12.5%, $P < .0001$), managing affect/emotionality (felt awkward: 37.5% vs 23.0%, $P = .0002$), and dealing with interpersonal relationships (difficulty making friends: 21.1% vs 14.5%, $P = .0405$; difficulty maintaining friendships: 21.9% vs 11.0%, $P = .0007$).

School/work. Significantly greater percentages of ADHD than non-ADHD participants reported difficulties with school/work, particularly in focusing on work (50.4% vs 10.4%, $P < .0001$) and school tasks (45.7% vs 18.2%, $P = .0187$); being organized (42.3% vs 11.3%, $P < .0001$) and productive (34.3% vs 11.3%, $P < .0001$) at work; and completing tasks on time at work (28.3% vs 5.2%, $P < .0001$).

Relationships. Significantly greater percentages of ADHD than non-ADHD participants reported difficulties in their relationships (interpersonal communication: 27.1% vs 11.5%, $P < .0001$; frustrating [35.1% vs 9.0%, $P < .0001$] and irritating [26.8% vs 8.0%, $P < .0001$] friends and family). A significantly greater percentage of ADHD participants

acknowledged challenges in maintaining friendships (21.6% vs 10.0%, $P = .0003$) and being in romantic relationships (16.1% vs 9.5%, $P = .0217$).

Impairment Among ADHD Subgroups

Everyday life. Significantly greater percentages of participants in the SA and LA subgroups versus the AU subgroup indicated they had difficulty finishing tasks (72.3% and 69.7% vs 54.2%, respectively, $P = .0002$ and $P = .0008$). A significantly greater percentage of participants in the LA versus the AU subgroup (56.2% vs 41.4%, $P = .0017$) reported difficulty being organized in daily life; the difference between the SA and AU subgroups approached significance (50.0% vs 41.4%, $P = .0831$). Significantly greater percentages of participants in the LA subgroup (58.7%) reported a lack of motivation versus the AU subgroup (41.0%, $P = .0002$); the difference between the LA and SA (58.7% vs 48.8%) subgroups approached significance ($P = .0578$). Forgetfulness was reported by a significantly greater percentage of participants in the LA (60.7%) than the AU (47.4%, $P = .0049$) and SA (43.4%, $P = .0009$) subgroups.

Home. A significantly greater percentage of participants in the LA versus the AU and SA subgroups reported difficulties managing household chores (55.7% vs 43.8% [$P = .0117$] and 45.2% [$P = .0444$], respectively) and sleeping (48.3% vs 29.7% [$P < .0001$] and 37.3% [$P = .0358$]).

School/work. A significantly greater percentage of participants in the AU subgroup than the SA subgroup reported difficulty taking notes (43.1% vs 17.1%, $P = .0101$).

Social life and relationships. There were no significant differences among the ADHD subgroups regarding challenges in their social life or relationships.

Satisfaction With Medication

Overall, ADHD participants were satisfied with their medication (Table 2). Mean satisfaction scores were lowest for duration of effect among all ADHD participants and significantly lower in the SA and AU subgroups versus the LA subgroup (both $P < .05$). There were no significant differences between ADHD subgroups for symptom control.

Medication Choice

Duration of effect was an important factor for participants in choosing their current medication (43.5%), with doctor's recommendation (59.6%) and insurance coverage (48.4%) also being important factors. The most frequently reported reason for augmentation in the AU subgroup was that 1 dose does not last long enough (Figure 2A). A significantly greater percentage of participants in the LA (67.7%) than AU subgroup (53.4%, $P = .0022$) chose their current medication based on the doctor's recommendation, with the difference between the LA and SA subgroups approaching significance (67.7% vs 59.0%, $P = .0871$).

Forty-five percent of ADHD participants reported that they liked how long their current medication lasted, with the percentage being significantly greater in the LA (60.7%) than the SA (16.2%, $P < .0001$) and AU (51.4%, $P = .0486$)

Table 2. Participant Satisfaction With Current ADHD Medication

Satisfaction Score ^b	Total ADHD (N=616)	SA (n=166)	LA (n=201)	AU (n=249)	P Value ^a		
					SA vs LA	SA vs AU	LA vs AU
Overall							
Mean (SD)	7.74 (1.82)	7.55 (1.89)	7.85 (1.83)	7.77 (1.77)	NS	NS	NS
Median	8	8	8	8	NS	NS	NS
Regimen/schedule							
Mean (SD)	8.13 (1.98)	7.90 (2.00)	8.90 (1.51)	7.66 (2.12)	<.05	NS	<.05
Median	8	8	10	8	NS	NS	NS
Onset							
Mean (SD)	7.91 (1.96)	7.89 (1.97)	8.06 (2.03)	7.80 (1.90)	NS	NS	NS
Median	8	8	8	8	NS	NS	NS
Symptom control							
Mean (SD)	7.69 (1.93)	7.48 (2.06)	7.91 (1.89)	7.65 (1.87)	NS	NS	NS
Median	8	8	8	8	NS	NS	NS
Side effects							
Mean (SD)	7.65 (2.07)	7.43 (2.15)	7.97 (2.04)	7.54 (2.01)	<.05	NS	NS
Median	8	8	8	8	NS	NS	NS
Cost							
Mean (SD)	6.90 (2.97)	7.40 (2.61)	6.48 (3.31)	6.92 (2.86)	<.05	NS	NS
Median	8	8	7	8	NS	NS	NS
Duration of effect							
Mean (SD)	6.88 (2.27)	6.64 (2.26)	7.45 (2.23)	6.58 (2.24)	<.05	NS	<.05
Median	7	7	8	7	NS	NS	NS

^aBased on analysis of variance, with post hoc Tukey tests.

^bBased on an 11-point scale (0=very dissatisfied to 10=very satisfied).

Abbreviations: ADHD=attention-deficit/hyperactivity disorder, AU=augmenter medication group, LA=long-acting medication group, NS=not significant, SA=short-acting medication group.

subgroups. Overall, 41.7% of ADHD participants reported that they had to plan activities around their medication wearing off, with the percentage being significantly greater in the AU (49.8%) than the SA (38.6%, $P=.0242$) and LA (34.3%, $P=.0010$) subgroups. A majority (55.8%) of ADHD participants indicated that the ideal medication would last all day, with this percentage being significantly lower in the SA (46.4%) than the LA (63.2%, $P=.0013$) and AU (56.2%, $P=.0493$) subgroups.

Challenging Times of the Day

The most challenging time of day was the afternoon for ADHD participants (43.7% vs 29.0% for non-ADHD participants, $P=.0002$) and early morning for non-ADHD participants (33.0% vs 33.1% for ADHD participants, $P=.9757$; Figure 2B). A significantly greater percentage of ADHD than non-ADHD participants reported midmorning to be the most challenging time of day (25.6% vs 16.5%, $P=.0079$). The evening was challenging for 35.4% of ADHD participants and 28.5% of non-ADHD participants ($P=.0733$). Among the ADHD subgroups, a significantly greater percentage of participants in the LA (47.3%) versus the SA (31.9%, $P=.0029$) and AU (28.1%, $P<.0001$) subgroups reported the evening to be a challenging time of day. A significantly greater percentage of the AU (30.9%) than the LA (20.9%, $P=.0165$) subgroups reported that midmorning was challenging (Figure 2B).

Medication Wearing Off

Participants with ADHD indicated experiencing effects of their medication wearing off, with >90% of participants

reporting 1 (11.7%) to ≥ 4 (45.1%) effects. Effects reported by >10% of ADHD participants included having trouble focusing (62.5%), becoming scattered and disorganized (50.3%), feeling tired (42.9%), not performing tasks as well (42.4%), slowing down physically (39.3%), getting fidgety (29.7%), becoming moody and irritable (28.4%), and getting hungry (20.9%). Only 6.8% of ADHD participants could not tell when their medication was wearing off.

Participants frequently noted that their medication wearing off negatively affected their ability to manage schoolwork/homework, work and household responsibilities, emotional responses or mood, and relationships (Table 3). Significantly lower percentages of the AU subgroup reported no effect and higher percentages reported a positive effect regarding their medication wearing off on various relationships, including with their children and on their ability to be a responsible parent, than the SA and LA subgroups.

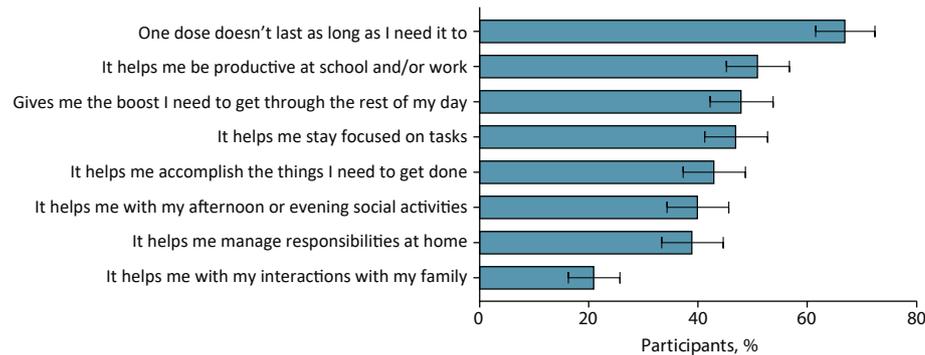
DISCUSSION

This survey demonstrates that adults being treated for ADHD continue to experience substantial impairment in multiple aspects of daily life. Greater percentages of ADHD than non-ADHD participants reported impairments and challenges at home, school, and work and in their relationships. ADHD participants reported experiencing difficulties at all times of the day, with the greatest percentages acknowledging challenges in the afternoon and evening when their medication was likely to have worn off. A significantly higher percentage of participants in the LA group than the SA or AU groups reported that the evening

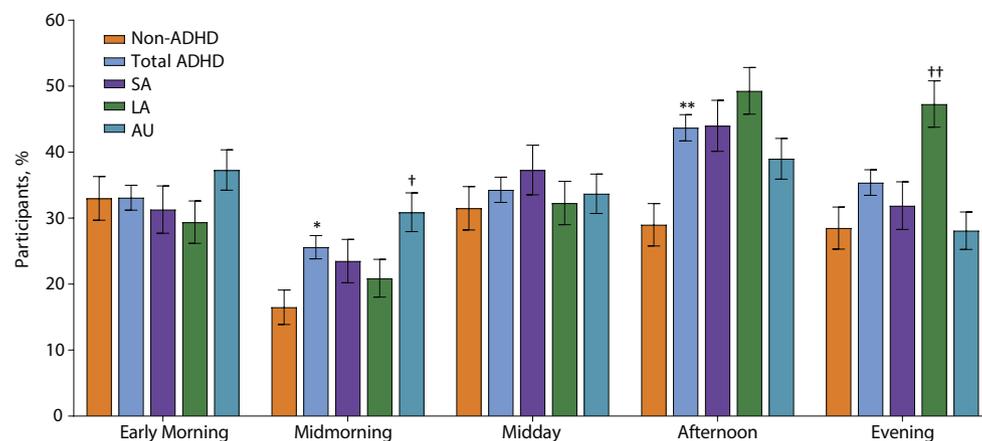
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Figure 2. (A) Reasons for Augmentation of Current ADHD Medication (n = 75) and (B) Challenging Times of the Day for Participants With ADHD (multiple responses could be selected)^a

A. Reasons for Augmentation



B. Challenging Times of Day^{b,c}



^aError bars represent the standard error.

^bBased on χ^2 tests (* P < .01, ** P < .001) vs non-ADHD group.

^cBased on χ^2 tests († P < .05 [vs LA subgroup], †† P < .0001 [vs the SA and AU subgroups]).

Abbreviations: ADHD = attention-deficit/hyperactivity disorder, AU = augmenter medication group, LA = long-acting medication group, SA = short-acting medication group.

was challenging. Although seemingly counterintuitive, this could be the result of the participants' current LA medication not having a sufficient duration of effect. This finding suggests that some participants in the LA group would have benefited from a longer-acting medication or from augmenting with another medication later in the day.

Duration of effect was an important factor for treatment choice and satisfaction, and a majority of ADHD participants reported that the ideal medication would last all day. In support of these findings, the highest level of satisfaction with duration of effect was reported by the LA group, with no difference observed between the SA and AU groups. However, across the ADHD groups, there were no significant differences in overall treatment satisfaction. This finding is not unexpected because many factors are likely to contribute to overall treatment satisfaction.

To fully understand adult ADHD, it is important to characterize the type and timing of impairment experienced.³⁰ Previous studies^{5,9,31–35} in adults and adolescents indicate that ADHD is associated with greater impairment in

various aspects of life compared with those without ADHD, resulting in a decreased quality of life. For example, the Lifetime Impairment Survey assessed the degree to which ADHD impairs everyday life and identified the areas of life most affected by ADHD.^{33,36} In adults with ADHD in the United Kingdom, greater impairments in social, family, emotional, academic, cognitive, and behavioral functioning were reported compared with those without ADHD.³³

There is limited guidance available for treating adult ADHD in the United States. Pharmacotherapy is recommended for adults with ADHD, especially those with moderate or severe levels of impairment, as part of a comprehensive treatment program.^{37,38} Even with pharmacotherapy, some individuals with ADHD experience residual symptoms and functional impairments.^{19,39–41} A qualitative interview study³⁵ conducted in the United Kingdom in adults with ADHD reported that individuals undergoing pharmacotherapy still experienced impairment in interpersonal relationships and work achievements. These findings are consistent with those of the current report and

Table 3. Effect of ADHD Medication Wearing Off

Effect, n (%)	Total ADHD	SA	LA	AU	P Value ^a		
					SA vs LA	SA vs AU	LA vs AU
Managing schoolwork/homework	n=356	n=96	n=92	n=168			
Negative effect	190 (53.4)	54 (56.3)	55 (59.8)	81 (48.2)	.1780	.0871	.0001
Negative and positive effect	46 (12.9)	14 (14.6)	9 (9.8)	23 (13.7)			
Positive effect	64 (18.0)	12 (13.5)	6 (6.5)	45 (26.8)			
No effect	56 (15.7)	15 (15.6)	22 (23.9)	19 (11.3)			
Managing responsibilities at work	n=510	n=144	n=158	n=208			
Negative effect	250 (49.0)	63 (43.8)	78 (49.4)	109 (52.4)	.0498	.0004	<.0001
Negative and positive effect	72 (14.1)	26 (18.1)	17 (10.8)	29 (13.9)			
Positive effect	82 (16.1)	20 (13.9)	12 (7.6)	50 (24.0)			
No effect	106 (20.8)	35 (24.3)	51 (32.3)	20 (9.6)			
Managing household responsibilities	n=608	n=163	n=198	n=247			
Negative effect	307 (50.5)	77 (47.2)	106 (53.5)	124 (50.2)	.0549	.1800	<.0001
Negative and positive effect	91 (15.0)	28 (17.2)	28 (14.1)	35 (14.2)			
Positive effect	85 (14.0)	23 (14.1)	11 (5.6)	51 (20.6)			
No effect	125 (20.6)	35 (21.5)	53 (26.8)	37 (15.0)			
Managing emotional responses or mood	n=603	n=163	n=196	n=244			
Negative effect	235 (39.0)	58 (35.6)	79 (40.3)	98 (40.2)	.2549	.0111	<.0001
Negative and positive effect	127 (21.1)	36 (22.1)	42 (21.4)	49 (20.1)			
Positive effect	71 (11.8)	16 (9.8)	9 (4.6)	46 (18.9)			
No effect	170 (28.2)	53 (32.5)	66 (33.7)	51 (20.9)			
Relationship with spouse/partner	n=483	n=129	n=147	n=207			
Negative effect	132 (27.3)	29 (22.5)	32 (21.8)	71 (34.3)	.7737	<.0001	<.0001
Negative and positive effect	105 (21.7)	33 (25.6)	34 (23.1)	38 (18.4)			
Positive effect	64 (13.3)	9 (7.0)	8 (5.4)	47 (22.7)			
No effect	182 (37.7)	58 (45.0)	73 (49.7)	51 (24.6)			
Relationship with colleagues	n=528	n=147	n=161	n=220			
Negative effect	131 (24.8)	31 (21.1)	38 (23.6)	62 (28.2)	.2231	<.0001	<.0001
Negative and positive effect	89 (16.9)	23 (15.6)	22 (13.7)	44 (20.0)			
Positive effect	68 (12.9)	11 (7.5)	9 (5.6)	48 (21.8)			
No effect	240 (45.5)	82 (55.8)	92 (57.1)	66 (30.0)			
Friendships	n=584	n=156	n=194	n=234			
Negative effect	122 (20.9)	28 (17.9)	38 (19.6)	56 (23.9)	.4751	<.0001	<.0001
Negative and positive effect	104 (17.8)	28 (17.9)	27 (13.9)	49 (20.9)			
Positive effect	62 (10.6)	9 (5.8)	7 (3.6)	46 (19.7)			
No effect	296 (50.7)	91 (58.3)	122 (62.9)	83 (35.5)			
Relationship with parents	n=462	n=116	n=145	n=201			
Negative effect	79 (17.1)	17 (14.7)	23 (15.9)	39 (19.4)	.9341	<.0001	<.0001
Negative and positive effect	66 (14.3)	14 (12.1)	14 (9.7)	38 (18.9)			
Positive effect	55 (11.9)	6 (5.2)	6 (4.1)	43 (21.4)			
No effect	262 (56.7)	79 (68.1)	102 (70.3)	81 (40.3)			
Relationships with children	n=320	n=86	n=92	n=142			
Negative effect	69 (21.6)	20 (23.3)	20 (21.7)	29 (20.4)	.3307	.0018	<.0001
Negative and positive effect	59 (18.4)	19 (22.1)	16 (17.4)	24 (16.9)			
Positive effect	58 (18.1)	8 (9.3)	4 (4.3)	46 (32.4)			
No effect	134 (41.9)	39 (45.3)	52 (56.5)	43 (30.3)			
Ability to be a responsible parent	n=318	n=89	n=89	n=140			
Negative effect	68 (21.4)	22 (24.7)	19 (21.3)	27 (19.3)	.0310	.0021	<.0001
Negative and positive effect	53 (16.7)	20 (22.5)	9 (10.1)	24 (17.1)			
Positive effect	55 (17.3)	7 (7.9)	5 (5.6)	43 (30.7)			
No effect	142 (44.7)	40 (44.9)	56 (62.9)	46 (32.9)			

^aBased on χ^2 tests.

Abbreviations: ADHD = attention-deficit/hyperactivity disorder, AU = augmenter medication group, LA = long-acting medication group, SA = short-acting medication group.

suggest clinicians should monitor their patients for ADHD-associated impairments across various times of the day, activities, and settings.

The preferences and needs of adults with ADHD relating to pharmacotherapy have received limited attention.^{9,32,42} In examining the current study, participants reported that duration of effect was an important factor for medication choice and satisfaction, along with physician recommendations and insurance coverage. This finding is supported by another study,³³ which reported that, although the majority of adults with ADHD were satisfied with their

treatment, a longer duration of effect was identified as an area requiring improvement. It is interesting that the number of participants reporting severe or very severe ADHD symptoms in the SA group was higher than expected. Furthermore, in the overall ADHD group and the AU group, use of SA medication was reported more frequently than LA medication. Although relationships between medication dose titration/optimization and ADHD severity were not examined in this study, the high utilization of SA medications could indicate that these individuals' ADHD symptoms were not optimally managed.

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It is important to note that study participants reported relatively high satisfaction scores for symptom control despite concurrently reporting considerable ADHD-associated impairments. This finding suggests that adults with ADHD may not always identify all of the aspects of impaired function associated with their ADHD symptoms and highlights that clinicians should ask their patients about symptom control and daily functioning. This approach would allow the clinician to discern where and how ADHD symptoms may continue to affect their patients' lives. It is also worth noting that participants are likely to have experienced improvement in symptoms and daily life because of treatment, which could have contributed to the levels of treatment satisfaction observed in this study.

The impairments reported in this study suggest some individuals with ADHD may need a longer-acting medication to manage their symptoms throughout the day. Although the largest percentage of ADHD participants reported the afternoon hours as the most problematic time of day, a substantial minority reported impairment in interpersonal relationships, home life, and social life during the evening. Accordingly, physicians should consider tailoring treatment for adults with ADHD to meet the variety of individual patient needs throughout the day.

Previous studies⁴³ indicate that the likelihood of medication compliance decreases as the number of daily doses increases. This finding suggests that missed doses could be an issue in individuals required to take ≥ 2 daily medication doses to manage their symptoms throughout the day. Consequently, LA formulations have largely replaced SA formulations as first-line ADHD treatments because a longer duration of effect is achieved with once-daily dosing.^{44,45} However, some patients may avoid LA formulations because of safety/tolerability concerns or personal beliefs that ADHD symptoms cause only workplace impairment.⁴⁶⁻⁴⁸ Alternatively, some patients may prefer augmentation of an LA formulation with an SA formulation because it allows them to experience less appetite suppression or feel more relaxed when the medication is not active, while allowing them to target specific times later in the day when they need to reintroduce the medication (eg, periods of homework or other activities in the evening).

This study has several limitations that could affect the generalizability of these data to a heterogeneous ADHD population. First, there is a potential for selection bias because participants were recruited through research participant panels, which may not be representative of the entire ADHD population. Second, the sex ratio of ADHD in adults is almost 1:1,^{49,50} but this study included a greater percentage of women. Third, non-ADHD participants were not matched with ADHD participants across all sociodemographic aspects. Nevertheless, many of the sociodemographic characteristics in the ADHD and non-ADHD groups were similar to those reported in another large survey⁹ conducted in the United States. Fourth, study participants were living in the United States, which may limit the relevance of these findings to other countries.

Fifth, the AU subgroup was considered as a single group in this study. However, augmentation patterns in this group were likely heterogeneous and examining different patterns of augmentation (ie, use of a SA medication > 2 times a day versus use of a SA plus a LA medication) may have yielded different results. Sixth, the relationship between medication dose titration/optimization and ADHD symptoms could not be addressed because this information was not collected. Lastly, reports of the diagnosis and treatment of ADHD were self-reported and not physician confirmed. Thus, participants who did not meet the study entry criteria may have been included.

CONCLUSION

Currently available ADHD medications effectively reduce ADHD symptoms and improve many aspects of life in adults with ADHD. However, this study demonstrates that adults with ADHD being treated with pharmacotherapy continue to report impaired daily function. Overall, adults with ADHD reported impairment across multiple settings and, regardless of medication type, reported that there were some negative effects associated with their medication wearing off. Overall satisfaction with medication was high across all ADHD subgroups despite reports of impairment; however, participants in the LA subgroup had the highest satisfaction with their medication's duration of effect and regimen/schedule. Although a proportion of participants from each ADHD subgroup reported challenges throughout the day, a significantly greater percentage of participants in the LA subgroup than the SA and AU subgroups reported that the evening was challenging. Furthermore, study participants described areas of unmet need, especially with respect to duration of treatment effect. The effects and challenges of ADHD symptoms across multiple dimensions of daily life emphasizes the need for clinicians to inquire about a patient's daily functioning at specific times and for specific activities to help better tailor the patient's treatment regimen so it optimizes coverage throughout the day.

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a CHC Group company, for support in writing and editing this manuscript.

Disclaimer: Shire, a member of the Takeda group of companies, develops and markets treatments for psychiatric disorders, including attention-deficit/hyperactivity disorder.

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Supplementary material: See accompanying pages.

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Supplementary material follows this article.

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THE PRIMARY CARE COMPANION FOR CNS DISORDERS

Supplementary Material

Article Title: The Patient Perspective: Unmet Treatment Needs in Adults With Attention-Deficit/Hyperactivity Disorder

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DOI Number: <https://doi.org/10.4088/PCC.18m02397>

List of Supplementary Material for the article

1. [Appendix A: Burden Survey for ADHD Population](#)
2. [Appendix B: Burden Survey for Normative Population](#)

Disclaimer

This Supplementary Material has been provided by the author(s) as an enhancement to the published article. It has been approved by peer review; however, it has undergone neither editing nor formatting by in-house editorial staff. The material is presented in the manner supplied by the author.

Appendix A: Burden Survey for ADHD Population

Thank you for your interest in participating in this study. First, we need to ask you a few questions in order to determine if you are eligible to participate.

1. Have you been diagnosed by a physician with any of the following conditions? Please select all that apply.

- Diabetes
- Attention Deficit/Hyperactivity Disorder (ADHD) **[Screen out if not selected]**
- Colon cancer
- Asthma
- Seasonal allergies
- Heartburn
- Gas
- GERD (Gastroesophageal Reflux Disease)
- Hypertension (high blood pressure)
- Dementia (including Alzheimer's disease) **[Screen Out]**
- Schizophrenia **[Screen Out]**
- Schizoaffective Disorder **[Screen Out]**
- Schizophreniform Disorder **[Screen Out]**
- Brief Psychotic Disorder **[Screen Out]**
- Delusional Disorder **[Screen Out]**
- Shared Psychotic Disorder **[Screen Out]**
- Substance-induced Psychotic Disorder **[Screen Out]**
- Psychotic Disorder Due to a Medical Condition **[Screen Out]**
- Paraphrenia **[Screen Out]**
- Substance Abuse/Dependency **[Screen Out]**
- None of the above **[screen out if selected]**

[Next screen]

2. Are you currently taking prescription medication to treat your ADHD?

- Yes
- No **[screen out]**

[Next screen]

3. What prescription medication(s) are you currently taking for your ADHD? Please select all that apply. **[insert drop down list of medications]**

Amphetamines – short-acting:

- Adderall® (mixed amphetamine salts – immediate release)

- Dextrostat ((dextroamphetamine sulfate)
- ProCentra® (dextroamphetamine sulfate)
- Zenzedi® (dextroamphetamine sulfate)

Amphetamines – long-acting:

- Adderall XR® (mixed amphetamine salts – extended release)
- Adzenys XR-ODT® (amphetamine extended-release orally disintegrating tablet)
- Dexedrine® Spansule® (dextroamphetamine sulfate spansule)
- Evekeo® (amphetamine sulfate)
- Vyvanse® (lisdexamfetamine dimesylate)

Methylphenidate – short-acting:

- Attenta® (methylphenidate immediate release)
- Focalin® (dexmethylphenidate hydrochloride)
- Medikinet® (methylphenidate immediate release)
- Metadate® (methylphenidate immediate release)
- Methylin® (methylphenidate immediate release)
- Penid® (methylphenidate immediate release)
- Ritalin IR® (methylphenidate immediate release)
- Ritalina® (methylphenidate immediate release)
- Rilatine® (methylphenidate immediate release)
- Rubifen® (methylphenidate immediate release)
- Tranquilyn® (methylphenidate immediate release)

Methylphenidate – long-acting:

- Aptensio XR® (methylphenidate HCL extended release)
- Concerta® (OROS-methylphenidate; or Methylphenidate ER)
- Daytrana® (methylphenidate transdermal patch)
- Focalin XR® (dexmethylphenidate hydrochloride extended release)
- Metadate CD® (methylphenidate HCL extended release capsules)
- Metadate ER® (methylphenidate extended release)
- Methylin ER® (methylphenidate extended release)
- Quillivant XR® (methylphenidate HCL extended-release oral suspension)
- QuilliChew ER® (methylphenidate HCL extended-release chewable tablet)

- Ritalin LA[®] (methylphenidate HCl extended release capsules)
- Ritalin SR[®] (methylphenidate HCL controlled release tablets)

Non-stimulants – short-acting:

- Tenex[®] (guanfacine – immediate release)

Non-stimulants – long acting:

- Intuniv[®] (guanfacine XR or guanfacine HCl extended release)
- Kapvay[®] (clonidine)
- Strattera[®] (atomoxetine)

Other:

- Other, please specify: _____ **[insert open text field]**
[if selected, ask: Is this a short-acting or long-acting medication?
 - Short-acting**
 - Long-acting]**

[Next screen]

[Ask 3a for each medication selected in SQ3]

3a. When did you start taking **[insert medication name]**? Please give your best estimate.

Month/year **[insert drop down]** **[Exclude if less than six months prior to screening]**

[Next screen]

3b. You indicated that you currently take **[insert medication name]** to treat your ADHD. How many times per day do you typically take **[insert medication name]**?

- 1
- 2
- 3
- 4 or more

[Next screen]

4. What is your age?

_____ **[show dropdown list, 0-99] [Screen out if under 18]**

[Next screen]

5. What is your gender?

- Male
- Female

[Next screen]

6. Are you currently attending school or taking classes?

- Yes **[ask Q6a]**
- No **[skip to question 7]**

6a. In what type of program are you currently enrolled?

[All options are exclusive choice]

- High school/GED
- Associates degree
- Trade school
- Undergraduate degree (Bachelor's)
- Post-graduate degree (Master's, Doctoral)
- Certificate program

- Not enrolled in a formal program
- Other

6b. What is your typical schedule for attending classes?

- I attend classes full-time during the day only
- I attend classes full-time in the evening only
- I attend classes full-time with a mix of day and evening classes
- I attend classes part-time during the day only
- I attend classes part-time in the evening only
- I attend classes part-time with a mix of day and evening classes

[Next screen]

7. What is the highest level of education you have completed?

[All options are exclusive choice]

- Less than high school
- High School/GED
- Some college (no degree)
- Associates degree
- Trade school
- Undergraduate degree (Bachelor's)
- Post-graduate degree (Master's, Doctoral)

[Next screen]

8. How would you describe your current employment status? Please select the answer that best applies.

[All options are exclusive choice]

- Employed, full-time **[ask 8a]**

- Employed, part-time **[ask 8a]**
- Self-employed **[ask 8a]**
- Stay-at-home parent/homemaker
- Student
- Unemployed
- Retired
- Disabled
- Other

8a. What is your typical work schedule?

- I work during the day only
- I work during the day, and sometimes into the evening
- I work during the evening only
- I work overnight only
- My schedule varies – I work a mix of days, evenings, and/or overnight

[Next screen]

9. Would you be willing to complete an online survey that lasts about 30 minutes?

- Yes
- No **[screen out if selected]**

[Next screen]

[IF RESPONDENT IS ELIGIBLE, PROCEED WITH THE FOLLOWING RECRUITMENT MESSAGE]

Based upon the answers you provided, you are eligible to participate in an online survey about your experiences with treating and managing ADHD.

Length of survey: About 30 minutes

Payment: **[Insert relevant amount]**

Survey is open only until we have reached the number of participants that we would like to complete the survey. Don't miss this opportunity!

The survey is designed to be completed in one session. However, if you need to leave partway through the survey, just click the link provided in the original email invitation, and you will be returned to where you left off. You will be paid after completing and submitting the survey, so please make sure that you complete the survey as quickly as possible to avoid being closed out of this opportunity.

If you are ready to begin now, click "Next" to read more about the study and provide consent to participate.

[Include "back" and "next" buttons at the bottom of each screen]

[Next screen]

WELCOME

We appreciate you taking the time to complete this survey. Your opinion is very important to us.

The purpose of this survey is to learn about your experiences with ADHD, treatment and your communications with your healthcare providers.

The next screen will tell you more about the study, including any risks and benefits of participating. Please read this page carefully, and, if you still would like to participate, please select the option at the bottom of the next screen indicating that you agree to take this survey.

[Next screen]

[Insert ICD]

AGREEMENT TO PARTICIPATE

This consent document contains important information to help you decide if you want to be in this study. If you have any questions that are not answered in this consent document, please contact the Principal Investigator.

I have read and understand the above information. I hereby voluntarily consent and offer to take part in this study and give permission to use the information I provide to take part in the study.

Check one box:

[Print a copy of this consent to keep for your records.](#)

- I have read the above statement, and I agree to participate in this study.
- I have read the above statement, and I do not agree to participate in this study. **[If selected, show: You've indicated that you do not agree to participate in this study. Is that correct? Yes/No. If YES, END SURVEY]**

[Next screen]

INTRODUCTION

Thank you for agreeing to participate in this survey. Before you begin, please note that the survey will take about 30 minutes to complete. If you need to leave the survey part-way through, you can re-enter the survey at the point where you left off using the survey link.

If you have any questions about the study or the survey, or if you need technical assistance, please call:

[Insert number] (Monday-Friday, **[Insert available times]**).

We recommend writing this number down or printing this page before you begin the survey.

Your responses will be kept strictly confidential, and we ask you to be as honest as possible when answering the questions. We are very interested in your opinions. There are no right or wrong answers. The survey will begin on the next screen.

[Next screen]

Section 1: You and Your Experience with ADHD

In this section of the survey, we will ask you questions about you, your diagnosis with ADHD and your experience with your doctor. Please answer each question as best as you can.

[Next screen]

Diagnosis

1. At what age were you diagnosed with ADHD? Please provide your best estimate.

_____years old **[insert drop-down box with 0-99]**

2. What symptoms or behaviors first led you to see a healthcare provider about your ADHD? Please select all that apply.
 - Inattentive (For example, short attention span, difficulty staying on-task, easily distracted, inability to finish tasks, trouble organizing, forgetful in daily activities, frequently losing things)
 - Hyperactive (For example, restless – need to move or fidget, talking excessively, “on the go” or “driven by a motor”, unable to work or function quietly when socially expected)
 - Impulsive (For example, blurting answers or responses before questions are completed, trouble waiting turn, often interrupting others, impulsive reactions)
 - Difficulty at work or school
 - Difficulty with social interactions and activities
 - Difficulty with relationships
 - Difficulty managing responsibilities
 - Difficulty parenting
 - Behavioral problems
 - Moody
 - Frequently not on time
 - Not sure – my parents took me when I was a child

[Next screen]

3. When did you first visit a healthcare provider about these symptoms and behaviors?
Please provide your best estimate.
_____ **[insert dropdown for year]**

[Next screen]

4. What type of healthcare provider did you **first** go to see about your ADHD?
[All options are exclusive choice]

- General practitioner/family doctor
- Pediatrician
- ADHD specialist
- Psychiatrist
- Physician Assistant
- Nurse Practitioner
- Psychologist
- Independent Clinical Social Worker
- Professional Clinical Counselor
- Marriage and Family Therapist
- Other
- Don't know

5. Did the **[insert HCP selected above]** you **first visited** diagnosis you with ADHD?
- Yes
 - No **[ask Q5a]**

5a. Who ultimately **diagnosed** you with ADHD?

[All options are exclusive choice]

- General practitioner/family doctor
- Pediatrician
- ADHD specialist
- Psychiatrist
- Physician Assistant
- Nurse Practitioner
- Licensed Psychologist
- Licensed Independent Clinical Social Worker
- Licensed Professional Clinical Counselor
- Licensed Marriage and Family Therapist
- Other
- Don't know

[Next screen]

5b. During the diagnosis process, were you initially **misdiagnosed** with a condition other than ADHD prior to receiving a final diagnosis for ADHD?

- Yes
- No
- Don't know

5ba. What was the misdiagnosis that you received? Please select only the condition that was inaccurately diagnosed. Do not include any conditions that you currently have in addition to ADHD.

- Aggression
- Anxiety
- Bipolar Disorder
- Conduct Disorder
- Depression
- Learning Difficulties (for example, dyslexia)
- Motor-Coordination Disorder
- Obsessive Compulsive Disorder
- Oppositional Defiant Disorder (ODD)
- Other
- Don't know

5bb. From the time you first were misdiagnosed, how long did it take you to receive the correct diagnosis of ADHD?

- Less than 1 month
- 1-2 months
- 3-6 months
- 7–12 months
- Greater than 12 months

[Next screen]

6. Were you referred to a special healthcare provider for evaluation and care of your ADHD?

- Yes
- No
- Don't know

[Next screen]

7. How long did it take from the time you first sought medical attention until you received a formal diagnosis for your ADHD?

[All options are exclusive choice]

- Immediate – received diagnosis on first visit to healthcare provider
- Less than 1 month
- 1-2 months
- 3-6 months
- 7–12 months
- Greater than 12 months
- Don't know

[Next screen]

8. Who do you **currently** see to treat your ADHD? Please select all that apply.

- General practitioner/family doctor
- Pediatrician
- ADHD specialist
- Psychiatrist
- Physician Assistant
- Nurse Practitioner
- Psychologist
- Independent Clinical Social Worker
- Professional Clinical Counselor
- Marriage and Family Therapist
- Other
- Don't know

[Next screen]

8a. You indicated that **[Insert HCP(s) from Q9]** treats your ADHD.

[If only one HCP selected, ask] Does this **[insert HCP]** prescribe your ADHD medication?

- Yes
- No

[If more than one HCP ask] Which of the following healthcare providers prescribes your ADHD medication?

[insert list of HCPs selected in Q9 for patient to select from]

[Next screen]

8b. Have you experienced any of the following issues related to accessing treatment for your ADHD? Please select all that apply.

- The out-of-pocket costs for my ADHD medication are high
- The out-of-pocket costs for visits to my ADHD healthcare provider(s) are high
- It's hard to get an appointment with my ADHD healthcare provider(s)
- It's difficult for me to travel to my appointments with my ADHD healthcare provider(s)
- It's difficult to take off school/work to get to appointments with my ADHD healthcare provider(s)
- My health insurance doesn't cover my preferred ADHD medication, so I have to take something else

- I have difficulty filling my prescription at my local pharmacy
- Other
- I haven't experienced any difficulties accessing treatment for my ADHD

[Next screen]

9. How would you describe the severity of your ADHD **currently**?

[All options are exclusive choice]

- Very mild
- Mild
- Moderate
- Severe
- Very severe

[Next screen]

10. Including your ADHD and non-ADHD medications, how many prescription medications do you take in total?

_____ prescriptions **[insert dropdown]**

11. Approximately how many pills per day do you take in total, including ADHD and non-ADHD prescription medication?

[All options are exclusive choice]

- 1 pill per day
- 2 pills per day
- 3 pills per day
- 4 pills per day
- 5 pills per day
- More than 5 pills per day

[Next screen]

Your responses are very important to us – thank you for your time!

[Next screen]

Section II: Treating Your ADHD

In this next section, we'll ask you some additional questions related to your ADHD treatment. For the following questions, please think about your experience with your **current** ADHD treatment.

[Next screen]

12. What expectations did you have when you began taking your **current ADHD medication**? Please select all that apply.
- I expected that it would take away all of my ADHD symptoms and behaviors
 - I expected that it would take away most of my ADHD symptoms and behaviors, but that some would continue
 - I expected the treatment would begin working right away
 - I expected that I would experience some treatment side effects
 - I didn't expect to experience any treatment side effects
 - I didn't know what to think
 - Other

[next screen]

[Repeat 13 and Q14 for each medication selected in screener Q3]

13. You indicated that you **currently** take **[insert medication from SQ3]** to treat your ADHD **[insert response from S3b]** time(s) per day.

14. How many **days per week** do you typically take **[insert medication name]**?

_____ days **[drop down with numbers 1 to 7]**

15. You indicated that you currently take both **[insert medication 1]** and **[medication 2 and so on]**. In what order do you take your medications?

Medication 1 – insert dropdown with “first,” “second,” etc.

- a. At what time do you normally take your first dose of **[Medication 1]**? **[Insert dropdown with times]**
- b. **[If relevant, ask]** At what time do you normally take your second dose of **[Medication 1]**? **[insert dropdown with times]** Repeat for third dose, fourth, etc... as necessary.

Medication 2 – insert dropdown

- a. At what time do you normally take your first dose of **[Medication 2]**? **[Insert dropdown with times]**
- b. **[If relevant, ask]** At what time do you normally take your second dose of **[Medication 2]**? **[insert dropdown with times]**

Medication 3 – insert dropdown

- a. At what time do you normally take your first dose of **[Medication 3]**? **[Insert dropdown with times]**
- b. **[If relevant, ask]** At what time do you normally take your second dose of **[Medication 3]**? **[insert dropdown with times]**

[Next screen]

[Repeat Q16 for each current medication]

16. Thinking specifically about your medication and not the ADHD itself, do you have difficulty sleeping because of **[insert medication]**?

[All options are exclusive choice]

- Every night I take the medication (100% of the time)
- Almost every night I take the medication (75%-99% of the time)
- Most nights I take the medication (50-74% of the time)
- Some nights I take the medication (25%-49% of the time)
- On occasion when I take the medication (<25% of the time)

- Never

[Repeat Q17 for each current medication which is taken more than 1x per day]

17. You noted that you take **[insert medication] [# of times from Q13]** times per day. For what reasons do you take more than one dose of **[insert medication name]**? Please select all that apply.

- One dose doesn't last as long as I need it to
- It helps me be productive at school and/or work
- It helps me with my afternoon or evening social activities
- It helps me manage responsibilities at home
- It helps me with my interactions with my family
- Gives me the boost I need to get through the rest of my day
- It helps me accomplish the things I need to get done
- It helps me stay focused on tasks
- Other

[Ask Q17a to those who take one dose per day of two or more medications]

17a. You noted that you take **[insert names of all ADHD meds]**. For what reasons do you take more than one medication per day? Please select all that apply.

- One dose doesn't last as long as I need it to
- It helps me be productive at school and/or work
- It helps me with my afternoon or evening social activities
- It helps me manage responsibilities at home
- It helps me with my interactions with my family
- Gives me the boost I need to get through the rest of my day
- It helps me accomplish the things I need to get done
- It helps me stay focused on tasks
- Other

[Next screen]

[Ask Q18-23 for each current medication]

18. How often do you miss a dose of **[insert medication]**?

[All options are exclusive choice]

- More than once a week
- Once a week
- A few times a month
- Once a month
- Once every few months
- Once every six months
- Once a year
- I never miss a dose **[Skip to Q20]**

[Next screen]

19. For what reasons do you sometimes miss a dose of **[insert medication]**? Please select all that apply.

- I intentionally choose not to take it **[ask Q19a]**
- I forget to take it
- I run out of medication
- I don't have my medication with me at the time of my dose
- Other

19a. For what reasons do you intentionally choose not to take a dose of **[Insert Medication]**? Please select all that apply.

- To avoid side affects
- I want to take a break from the medication
- I don't take it on the weekends
- I don't need to focus
- I want to relax
- I want to sleep
- I only take it for work/school
- Other

[Next screen]

[Ask Q19b, Q19ba, and Q19bb separately for each current medication]

19b. Do you ever **intentionally** take a dose of **[Insert Medication]** **later** than as prescribed?

- Yes **[Ask 19ba and 19bb]**
- No **[Skip to Q20]**

19ba. How often do you **intentionally** choose to take a dose of **[Insert Medication]** **later** than as prescribed?

- More than once a week
- Once a week
- A few times a month
- Once a month
- Once every few months
- Once every six months
- Once a year

[Next screen]

19bb. For what reasons do you **intentionally** take a dose of **[Insert Medication]** **later** than as prescribed? Please select all that apply.

- Because I have plans later in the day and want to ensure I am covered by my medication
- Because I have plans for which I don't want to be covered by the medication
- Because I want a break from the medication
- Because I don't feel that I need it at the time I'm scheduled to take it
- Other

[Next screen]

20. What do you **like** about **[insert medication]**? Please select all that apply.

- How well it controls my ADHD symptoms
- How often I have to take it
- How long it lasts
- How quickly it starts to work
- The side effects are manageable

- I don't have any side effects
- Helps me be more productive
- Helps me focus
- Helps me feel calm
- Gives me more energy
- Helps me feel less depressed
- Helps me feel more positive
- It decreases my appetite
- Improves my social interactions
- Available in many different dosages
- Easy to alter dose or strength of medication
- The cost
- Other
- There's nothing I like about this medication

[Next screen]

21. What do you **dislike** about **[insert medication]**? Please select all that apply.
- It's not effective enough at controlling my ADHD symptoms
 - It doesn't last long enough
 - It takes too long to start working
 - How often I have to take it
 - It gives me insomnia/hard to get to sleep
 - It gives me dry mouth
 - I don't like how my medication makes me feel
 - It makes my heart race
 - It decreases my appetite
 - Other side effects
 - I worry about it being addictive
 - The cost
 - Other
 - There's nothing I dislike about this medication

[Next screen]

22. At what time does **[insert medication]** usually wear off?

[All options are exclusive choice]

- Less than 2 hours after taking a dose
- 2-3 hours after taking a dose
- 4-5 hours after taking a dose
- 6-7 hours after taking a dose
- 8-9 hours after taking a dose

- 10-11 hours after taking a dose
- 12 hours after taking a dose
- More than 12 hours after taking a dose
- Don't know

[Next screen]

23. How can you tell that **[insert medication]** is wearing off? Please select all that apply.

- I start to have trouble focusing
- I feel tired
- I slow down physically
- I feel more relaxed
- I get hungry
- I start to feel more like myself
- I become scattered and disorganized
- I can't perform as well at tasks
- I get fidgety
- I become moody and irritable
- I get a headache
- Other
- I can't tell when my medication is wearing off

[Next screen]

24. Do you ever plan your activities around your medication wearing off?

- Yes **[ask Q24a]**
- No

24a. What activities do you plan around your medication wearing off? Please select all that apply

- Social activities
- Recreational/enjoyment activities
- Household chores
- Work responsibilities
- Making and going to appointments

- Running errands
- Doing schoolwork/homework
- Spending time with my friends/family
- Parental responsibilities
- Other

[Next screen]

25. Does your medication wearing off have an effect on:

- a. Your relationship with your spouse/partner
 - Yes – **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- b. Your relationship with your children
 - Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- c. Your ability to fulfill your responsibilities as a parent
 - Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- d. Your relationship with your parents
 - Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- e. Your friendships
 - Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- f. Your relationship with your colleagues

- Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- g. Your ability to manage household responsibilities (for example, cleaning, cooking, paying bills, feeding pets, etc....)
- Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- h. Your ability to manage your responsibilities at work
- Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- i. Your ability to do your schoolwork or homework successfully
- Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- j. Your ability to manage your emotional responses or mood
- Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable
- k. Your ability to participate in recreational/enjoyment activities
- Yes **[insert drop down – has a positive effect; has a negative effect; both]**
 - No
 - Not applicable

[Next screen]

26. Which of the following factors were important to you when choosing your **current** ADHD treatment regimen? Please select all that apply.
- How well I thought I could follow the treatment schedule
 - The treatment regimen (for example, how often I'd need to take it, how difficult it was to take, etc...)

- Insurance coverage for the treatment
- The type and severity of symptoms that I was experiencing
- How long the medication would last before wearing off
- How quickly the medication would start to work
- The type of side effects I might experience
- My doctor's recommendation
- Things I've heard from peers or read about different ADHD medications
- Other

26a. Please rank the factors you've identified as playing a role in selecting your **current ADHD treatment** in order of importance, with 1 being the factor you consider to be "most important," 2 the "second most important" and so on until all have received a ranking.

[Insert list of factors selected by respondent in Q26 in a format that allows them to be ranked in order of importance]

[Next screen]

27. Thinking about your overall ADHD medication treatment regimen, on a scale of 0 to 10, with 0 being "very dissatisfied" and 10 being "very satisfied," how **satisfied** are you with the treatment that you're **currently taking** for your ADHD?

[insert 0-10 NRS scale for patients to click on]

[Next screen]

28. Thinking about your overall ADHD medication treatment regimen, on a scale of 0 to 10, with 0 being "very dissatisfied" and 10 being "very satisfied," how **satisfied** are you with each of the following aspects of your **current** ADHD treatment? **[insert 0-10 NRS scale for patients to click on for each option below]**

- How well your current ADHD treatment has controlled your symptoms
- How long your current ADHD treatment lasts before wearing off
- How long it takes for your current ADHD treatment to start working
- How manageable/tolerable the side-effects of your current ADHD treatment are
- The regimen or schedule for taking your current ADHD treatment
- The amount you have to pay for your current ADHD treatment

[Ask 29 and 29a only to those who are currently taking only short-acting medications]

29. Have you ever considered going on a long-acting medication?

- Yes
- No

29a. What are the reasons you decided to stay on a short-acting medication? Please select all that apply.

- It was more affordable than long-acting
- My insurance provided better coverage of the short-acting medication
- Short-acting is more effective for me
- I like that it doesn't last as long
- Short-acting medication had less side effects
- My doctor wanted me to stay on short-acting
- Short-acting worked best for my work/school schedule
- Other

[Next screen]

30. If you could design your **ideal ADHD medication**, which features would be **important** to you? Please select all that apply.

- It wouldn't cause insomnia
- I'd need to take only one pill a day
- It would be more natural and holistic
- It wouldn't change my personality
- It wouldn't decrease my appetite
- It would last all day (from wake-up until bedtime)
- It would last just for the full work/school day
- It would only last part of the day
- My heart wouldn't race
- It would control my ADHD symptoms effectively
- It would be affordable
- I could take it only when I needed it
- Other

30a. Please rank the ideal ADHD medication features you've selected in order of importance, with 1 being the feature you consider to be "most important," 2 the "second most important" and so on until all have received a ranking.

[Insert list of factors selected by respondent in Q30 in a format that allows them to be ranked in order of importance]

[Next screen]

31. In general, how do you feel about taking ADHD medication? Indicate how much you agree or disagree with the following statements. **[Strongly agree, agree, neither agree or disagree, disagree, strongly disagree]. [Don't ask follow-up question for "other" response]**

- I know it helps me, but I don't like to take it
- Taking it doesn't bother me at all
- I don't like having to take any medication
- I am worried about it being addictive
- I like taking it because it helps me get through my day
- I don't like to tell others that I take medication
- I like taking it because it allows me to function better
- I don't like having to rely on medication to function
- Other

[Next screen]

You're making great progress! Thank you for your time!

[Next screen]**Section III. Activities of Daily Life**

The following set of questions asks you about a variety of difficulties that you may or may not experience in your daily life. **In cases where your answer might vary depending on whether you are on or off medication, think about times when you're on medication when answering.**

[For questions 32-39, please insert a follow up question (unless specified differently in the comments) for each checked response, except "other" and "I don't experience...": "On a scale of 0-10, with 0 being not at all bothersome and 10 being extremely bothersome, how bothersome is this issue for you? [Insert 0-10 NRS scale] AND "How often do you experience this issue? All the time/7 days a week / Most of the time/5-6 days a week / Some of the time/3-4 days a week / A little of the time/1-2 days a week / Rarely/Less than once a week

32. Do you experience any of the following challenges in your **every-day life** that you believe are because of your ADHD? Please select all that apply.

- Difficulty finishing tasks
- Difficulty with reading

- Difficulty with writing
- Difficulty with school work
- Difficulty being productive at work
- Difficulty communicating with others
- Difficulty having relationships with others
- Difficulty responding appropriately in social situations
- Difficulty in social gatherings
- Difficulty caring for children or handling parental responsibilities
- A lack of motivation
- Anxiety
- Feeling held back
- Feeling overwhelmed
- Stress
- Difficulty being organized at work
- Difficulty being organized in my daily life
- Forgetfulness
- Poor long-term memory
- Poor short-term memory
- Other
- I don't experience any challenges because of my ADHD

[Next screen]

33. Do you experience any of the following impacts on your **life at home** because of your ADHD? Please select all that apply.
- Difficulty paying bills on time
 - Difficulty completing a task
 - Difficulty keeping household organized
 - Difficulty managing household chores
 - Difficulty caring for children or handling parental responsibilities
 - Difficulty caring for pets
 - Difficulty sleeping at night
 - Other
 - I don't experience any difficulties at home because of my ADHD

[Next screen]

34. **Are you unable to do, or have more difficulty doing**, any of the following activities because of your ADHD? Please select all that apply.
- Reading
 - School work
 - Writing
 - Social activities
 - Driving
 - Holding conversations
 - Tasks requiring attention to detail

- Attending school
- Sitting for an extended period of time
- Hobbies
- Work tasks
- Organizing paperwork
- Prioritizing tasks
- Managing your emotional responses or mood
- Other
- I don't have any tasks that are more difficult to do or that I am unable to do because of my ADHD

[Next screen]

35. From the list below, are there any activities that you **would like to do that you don't do or avoid doing** because of your ADHD? Please select all that apply.

- Attending school
- Reading
- Being part of a social club or organization
- Making plans
- Tasks requiring attention to details
- Tasks requiring sitting still for an extended period
- Social activities
- Playing sports
- Attending sporting events
- House chores
- Sleeping
- Traveling
- Becoming a parent
- Participating in activities with my children
- Getting married
- Other
- I don't avoid any activities because of my ADHD

[Next screen]

36. Do you experience any of the following impacts on your **social life** because of your ADHD? Please select all that apply.

- Difficulty holding conversations
- I don't feel very social
- I feel awkward
- I tend to forget names
- I am more reserved
- I have difficulty making friends

- I have difficulty maintaining friendships
- I can't sit through a movie
- I forget to call friends
- I am late to social events
- I have difficulty focusing when with friends or family
- Other
- My social life is not impacted because of my ADHD

[Next screen]

[Ask Q37 only to those who have indicated that they are currently attending school in SQ6]

37. **At school**, do you experience any of the following because of your ADHD? Please select all that apply.
- I have difficulty focusing in class
 - I have difficulty focusing while doing school work
 - I have difficulty taking notes in class
 - I have difficulty prioritizing tasks
 - I get poor grades
 - I have trouble taking tests within the allotted time
 - It takes me a long time to complete required tasks
 - I have difficulty being on time to class
 - Other
 - I don't have any difficulties at school because of my ADHD

[Next screen]

[Ask Q38 only to those who have indicated that they are employed in SQ7]

38. Related to **work**, do you have difficulty with any of the following because of your ADHD? Please select all that apply.
- Being organized
 - Focusing on tasks
 - Forgetting to do simple tasks
 - Taking notes in meetings
 - Being productive
 - Being on time to work
 - Getting along with my co-workers
 - Getting along with my boss
 - Being engaged in meetings
 - Completing tasks on time
 - Keeping a job

- Communicating with others
- Other
- I don't have any difficulties at work because of my ADHD

[Next screen]

39. Do you experience any of the following difficulties in your **relationships with others** because of your ADHD? Please select all that apply.
- I have difficulty communicating with others
 - Friends and/or family get frustrated with me
 - I say things without thinking that hurt others or make them mad
 - I irritate my family and/or friends
 - I have trouble maintaining friendships
 - I have difficulty being in a long-term romantic relationship
 - Dating is difficult
 - Meeting new people is difficult
 - I often get into fights with friends and/or family members
 - I have difficulty listening to others
 - I have difficulty in my relationship with my children
 - Other
 - I don't have any relationship difficulties because of my ADHD

[Next screen]

40. Do you ever have days that you feel are more challenging than others because of your ADHD?
- Yes **[Ask Q40a]**
 - No
- 40a. What are some of the reasons those days are particularly challenging? Please select all that apply.
- I am under a lot of stress
 - I am trying to do too much
 - I am bored
 - I can't get everything done that I want to get done
 - I feel rushed
 - I haven't gotten enough sleep
 - I'm feeling overwhelmed
 - I have deadlines to meet
 - I'm having an extra hard time focusing
 - Other

[Next screen]

41. What **times of the day** are **most challenging** for you with regard to your ADHD?
Please select all that apply.
- Early morning
 - Mid-morning
 - Mid-day
 - Afternoon
 - Evening

[Next screen]

41A. During a typical week, what activities do you usually do **in the evenings (after 5 pm)**? Please select all that apply.

- Work
- Attend classes
- Do homework
- Take care of my children
- Help my children with their homework
- Make dinner
- Get my children ready for bed
- Spend time with friends and family at home
- Go out with friends/family
- Exercise
- Do recreational activities/hobbies
- Manage household responsibilities (for example, paying bills, running errands, doing chores, etc...)
- Relax at home
- Other

[Next screen]

42. Do you have difficulty sleeping because of your **ADHD symptoms**?

[All options are exclusive choice]

- Every night (100% of the time)
- Almost every night (75%-99% of the time)
- Most nights (50-74% of the time)
- Some nights (25%-49% of the time)
- On occasion (Less than 25% of the time)
- Never

[Next screen]

43. What is the **hardest** part about having ADHD? Please select the answer that **best** applies.

[All options are exclusive choice]

- Difficulty falling sleeping
- Difficulty staying asleep
- Feeling dependent on medication
- Managing my medication
- Managing medication side effects
- Having difficulty with relationships
- Having difficulty with social activities
- Having difficulty being successful at school/work
- Having difficulty focusing
- Remembering things
- Feeling different than others
- Having difficulty controlling myself
- Having trouble being organized
- Coming to terms with the diagnosis
- Having difficulty managing responsibilities at home
- Having difficulty with my spouse/partner
- Having difficulty with my children
- Having difficulty interacting with my family and friends
- Having difficulty completing tasks
- Being impulsive
- Other

[Next screen]

44. Are there times that you believe your ADHD is having a beneficial effect on your life?

- Yes [**ask Q44a**]
- No

44a. What do you think are the benefits of having ADHD? Please select all that apply.

- My creativity
- I am energetic
- I am able to hyper-focus on things I enjoy
- I feel excited about life
- I have an open mind
- I can think outside the box
- People think that I am fun to be around
- I'm great at brainstorming
- I am adventurous
- I can speak my mind

- Other

[Next screen]

45. On scale of 0-10, with 0 being not at all bothersome and 10 being extremely bothersome, how bothersome, on average, is having ADHD for you in your everyday life? **[insert NRS scale]**

[Next screen]

Section IV: Past ADHD Treatment Experience

46. You indicated that you are **currently** being treated with **[INSERT MEDICATIONS SELECTED FROM SQ3]** for your ADHD. Have you taken other treatments for your ADHD **in the past**?

- Yes **[ask 46a-c]**
 No **[skip to Q47]**
 Don't know **[skip to Q47]**

- 46a. What other treatments have you taken for your ADHD **in the past**? Please select all that apply.

[insert drop down list of medications]

[Next screen]

[Ask the following questions for each medication checked in Q46a]

- 46b. How long did you take **[Insert name of medication]**?

- Less than 6 months
 6 months to less than 1 year
 1-2 years
 3-4 years
 5 or more years

46c. What were the reasons you stopped taking **[Insert name of medication]**?
Please select all that apply.

- I didn't like the side effects and asked for a new treatment
- My ADHD healthcare provider decided to give me a new treatment because of the side effects I was having
- The medication was not controlling my ADHD symptoms as well as I wanted it to
- It was too expensive
- My insurance stopped covering the medication
- Other

[Next screen]

You are doing great, not much further!

[Next screen]

Section V: Communicating with Your Healthcare Provider

This next set of questions asks you about your experiences communicating with your healthcare provider regarding your ADHD.

[Next screen]

[Repeat Q47 for each HCP selected in Q8]

47. You indicated that you currently see a **[insert HCP from Q9]** to treat your ADHD. How often do you see him/her about your ADHD?

[All options are exclusive choice]

- Once a month
- Once every 3 months

- Once every 6 months
- Once a year
- More than once a year
- Other

[Next screen]

[Repeat Q48 for each HCP selected in Q8]

48. During visits with the **[insert HCP from Q8]** who treats your ADHD, how much time do you usually spend discussing your ADHD?

[All options are exclusive choice]

- Less than 5 minutes
- About 5 to less than 10 minutes
- About 10 to less than 15 minutes
- About 15 to less than 20 minutes
- About 20 minutes to less than 25 minutes
- About 25 to less than 30 minutes
- About 30 minutes or more

[Next screen]

[Repeat Q49 for each HCP selected in Q8]

49. Which of the following do you regularly discuss with your **[insert HCP from Q8]** during visits? Please select all that apply.
- How I am feeling in general
 - My ADHD symptoms and behaviors and whether they've changed since my last visit
 - Any side effects from my ADHD treatment
 - How my ADHD is impacting my daily activities, such as work, school, or taking care of my family

- How I'm doing with my relationships with friends and family
- How I'm doing emotionally
- Ways I can better manage my ADHD
- Resources I can access to help me with my ADHD
- Other treatment options
- Other

[For each option selected above, ask follow-up question]

49a. How is this usually brought up during the visit?

[All options are exclusive choice]

- My doctor specifically asks me about it or brings it up with me
- I bring it up on my own

[Next screen]

[Repeat Q50 for each HCP selected in Q8]

50. Do you feel that **[insert HCP from Q8]** generally gives you enough time to ask questions and share your concerns?
- Yes
 - No

[Next screen]

[Repeat Q51 for each HCP selected in Q8]

51. On a scale of 0 to 10, with 0 being "very dissatisfied" and 10 being "very satisfied," how satisfied are you with each of the following related to your **current [insert HCP from Q8]** concerning your ADHD care: **[Insert 0-10 NRS scale for each option below]**
- Overall communication with your **[insert HCP from Q8]** about your ADHD
 - The amount of time you spend with your **[insert HCP from Q8]**
 - Communication with your **[insert HCP from Q8]** about your ADHD treatment options

- The information you've received about ADHD in general from your **[insert HCP from Q8]**
- The information you've received from your **[insert HCP from Q8]** about resources to help you with your ADHD, such as counseling and support groups
- The overall care you receive from your **[insert HCP from Q8]**

[Next screen]

52. When deciding on your **current ADHD medication**, which of the following best describes **how** your ADHD healthcare provider(s) discussed your treatment options with you? Please select all that apply.
- My healthcare provider presented several different options for treatment and discussed each one with me, ultimately letting me decide which treatment I would take
 - My healthcare provider explained all of the side effects I might experience from each medication
 - I felt like my healthcare provider and I made a plan for my treatment as a team
 - My healthcare provider told me my options for treatment and then provided a recommendation
 - My healthcare provider told me what treatment I would take without much discussion
 - Other

[Next screen]

53. How **satisfied** were you with the ADHD treatment information that your healthcare provider(s) gave you?
- [Provide NRS scale with ranking 0 being "very dissatisfied" to 10 being "very satisfied"]**

[Next screen]

54. What could your ADHD healthcare provider(s) have done better to explain all treatment options? Please select all that apply.
- My healthcare provider could have discussed treatment options with me in more detail

- My healthcare provider could have shared more information about treatment side effects with me
- My healthcare provider could have involved me more in the decision-making process for selecting a treatment
- My healthcare provider could have better explained the logistics of refilling prescriptions (e.g. having to visit doctor every 1 month for a new prescription)
- Nothing
- Other

[Next screen]

Just a few last questions!

[Next screen]

Section VI: More Questions about You

And now we have a few more questions we would like to ask about you.

[Next screen]

55. Are you Hispanic or Latino?

- Yes
- No

56. Which of the following best describes your racial background?

[All options are exclusive choice]

- White (Origins in Europe, Middle East, North Africa)
- Black/African American (Origins in Black racial groups of Africa)
- Asian (Origins in Far East, Southeast Asia, Indian subcontinent)
- American Indian/Alaska Native (Origins in original peoples of North America who maintain tribal affiliations)
- Native Hawaiian/Other Pacific Islander (Origins in Hawaii, Guam, Samoa or other Pacific Islands)
- Multiracial

Prefer not to answer

[Next screen]

57. How many other people currently live with you at least 50% of the time?

_____ people **[insert drop down]**

[Next screen]

58. How many children, for whom you provide care, currently live with you at least 50% of the time?

_____ children **[insert drop down]**

[Next screen]

59. Please select the option below which best describes your current relationship status:

[All options are exclusive choice]

- Married
- Separated
- Divorced
- Widowed
- Living with partner
- In a serious relationship
- Single, not in a serious relationship
- Other

[Next screen]

60. Which of the following best describes your current annual household income?

[All options are exclusive choice]

- Less than \$24,999
- \$25,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$124,999
- \$125,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 or more
- Prefer not to answer

[Next screen]

61. What type of health insurance do you currently have?

Medicare or Medicaid

A plan through a Health Insurance Exchange (Also referred to as, Affordable Care Act/ObamaCare)

Health Maintenance Organization (HMO)

Preferred Provider Organization (PPO)

Point-of-Service Plan (POS)

Tricare (for members of the US military and their families)

Health care through the Veterans Administration (VA) (for US military veterans)

CHAMPVA (benefits for families of US military veterans)

Other

I don't have health insurance

Don't know

[Next screen]

62. Do you have a **current physician's diagnosis** of any of the following conditions?
Please select all that apply.

- Aggression
- Alcohol Abuse
- Anxiety
- Asperger Syndrome
- Autism
- Bipolar Disorder

- Cerebral Palsy
- Conduct Disorder
- Depression
- Substance/Drug Abuse
- Eating Disorder
- Epilepsy
- Learning Disability (Tested to have an IQ less than 70)
- Learning Difficulties (for example, dyslexia)
- Motor-Coordination Disorder
- Obsessive Compulsive Disorder
- Oppositional Defiant Disorder (ODD)
- Schizophrenia
- Schizoaffective Disorder
- Sleep Disorder (such as insomnia)
- Speech/Language Disorder
- Tourette's Syndrome
- None of the above **[Exclusive Choice]**

[Next screen]

63. How would you rate your current health overall?

[All options are exclusive choice]

- Excellent
- Very good
- Good
- Fair
- Poor

Appendix B: Burden Survey for Normative Population

Thank you for your interest in participating in this study. First, we need to ask you a few questions in order to determine if you are eligible to participate.

10. Have you been diagnosed by a physician with any of the following conditions? Please select all that apply.

- Diabetes
- Attention Deficit/Hyperactivity Disorder (ADHD) **[Screen out if selected]**
- Colon cancer
- Asthma
- Seasonal allergies
- Heartburn
- Gas
- GERD (Gastroesophageal Reflux Disease)
- Hypertension (high blood pressure)
- Dementia (including Alzheimer's disease) **[Screen Out]**
- Schizophrenia **[Screen Out]**
- Schizoaffective Disorder **[Screen Out]**
- Schizophreniform Disorder **[Screen Out]**
- Brief Psychotic Disorder **[Screen Out]**
- Delusional Disorder **[Screen Out]**
- Shared Psychotic Disorder **[Screen Out]**
- Substance-induced Psychotic Disorder **[Screen Out]**
- Psychotic Disorder Due to a Medical Condition **[Screen Out]**
- Paraphrenia **[Screen Out]**
- Substance Abuse/Dependency **[Screen Out]**
- None of the above **[Exclusive choice]**

[Next screen]

11. What is your age?
_____ **[show dropdown list, 0-99] [Screen out if under 18]**

[Next screen]

12. Do you currently take any of the following medications? **[Screen out if any are selected.]**

- Adderall[®] (mixed amphetamine salts – immediate release)
- Adderall XR[®] (mixed amphetamine salts – extended release)
- Adzenys XR-ODT[®] (amphetamine extended-release orally disintegrating tablet)
- Aptensio XR[®] (methylphenidate HCL extended release)
- Attenta[®] (methylphenidate immediate release)
- Concerta[®] (OROS-methylphenidate; or Methylphenidate ER)
- Daytrana[®] (methylphenidate transdermal patch)
- Dexedrine[®] Spansule[®] (dextroamphetamine sulfate spansule)
- Dextrostat[®] (dextroamphetamine sulfate)
- Evekeo[®] (amphetamine sulfate)
- Focalin[®] (dexmethylphenidate hydrochloride)
- Focalin XR[®] (dexmethylphenidate hydrochloride extended release)
- Intuniv[®] (guanfacine XR or guanfacine HCl extended release)
- Kapvay[®] (clonidine)
- Medikinet[®] (methylphenidate immediate release)
- Metadate[®] (methylphenidate immediate release)
- Metadate CD[®] (methylphenidate HCL extended release capsules)
- Metadate ER[®] (methylphenidate extended release)
- Methylin[®] (methylphenidate immediate release)
- Methylin ER[®] (methylphenidate extended release)
- Penid[®] (methylphenidate immediate release)
- ProCentra[®] (dextroamphetamine sulfate)
- Quillivant XR[®] (methylphenidate HCL extended-release oral suspension)
- QuilliChew ER[®] (methylphenidate HCL extended-release chewable tablet)
- Ritalin IR[®] (methylphenidate immediate release)
- Ritalin LA[®] (methylphenidate HCl extended release capsules)
- Ritalin SR[®] (methylphenidate HCL controlled release tablets)
- Ritalina[®] (methylphenidate immediate release)
- Rilatine[®] (methylphenidate immediate release)
- Rubifen[®] (methylphenidate immediate release)
- Strattera[®] (atomoxetine)
- Tenex[®] (guanfacine – immediate release)
- Tranquilyn[®] (methylphenidate immediate release)
- Vyvanse[®] (lisdexamfetamine dimesylate)
- Zenzedi[®] (dextroamphetamine sulfate)

13. What is your gender?

- Male
- Female

[Next screen]

14. Are you currently attending school or taking classes?

- Yes **[ask Q5a]**
- No **[skip to question 6]**

5a. In what type of program are you currently enrolled?

[All options are exclusive choice]

- High school/GED
- Associates degree
- Trade school
- Undergraduate degree (Bachelor's)
- Post-graduate degree (Master's, Doctoral)
- Certificate program
- Not enrolled in a formal program
- Other

5b. What is your typical schedule for attending classes?

[All options are exclusive choice]

- I attend classes full-time during the day only
- I attend classes full-time in the evening only
- I attend classes full-time with a mix of day and evening classes
- I attend classes part-time during the day only
- I attend classes part-time in the evening only
- I attend classes part-time with a mix of day and evening classes

[Next screen]

15. What is the highest level of education you have completed?

[All options are exclusive choice]

- Less than high school
- High School/GED
- Some college (no degree)
- Associates degree
- Trade school
- Undergraduate degree (Bachelor's)
- Post-graduate degree (Master's, Doctoral)

[Next screen]

16. How would you describe your current employment status? Please select the answer that best applies.

[All options are exclusive choice]

- Employed, full-time **[ask 7a]**
- Employed, part-time **[ask 7a]**
- Self-employed **[ask 7a]**
- Stay-at-home parent/homemaker
- Unemployed
- Retired
- Disabled
- Other

- 7a. What is your typical work schedule?

- I work during the day only
- I work during the day, and sometimes into the evening
- I work during the evening only
- I work overnight only
- My schedule varies – I work a mix of days, evenings, and/or overnight

[Next screen]

17. Would you be willing to complete an online survey that lasts about 10 minutes?

- Yes
- No **[screen out if selected]**

[Next screen]

[IF RESPONDENT IS ELIGIBLE, PROCEED WITH THE FOLLOWING RECRUITMENT MESSAGE]

Based upon the answers you provided, you are eligible to participate in an online survey about various impacts you might experience related to your daily activities.

Length of survey: About 10 minutes

Payment: **[Insert relevant amount]**

Survey is open only until we have reached the number of participants that we would like to complete the survey. Don't miss this opportunity!

The survey is designed to be completed in one session. However, if you need to leave partway through the survey, just click the link provided in the original email invitation, and you will be returned to where you left off. You will be paid after completing and submitting the survey, so please make sure that you complete the survey as quickly as possible to avoid being closed out of this opportunity.

If you are ready to begin now, click "Next" to read more about the study and provide consent to participate.

[Include "back" and "next" buttons at the bottom of each screen]

[Next screen]

WELCOME

We appreciate you taking the time to complete this survey. Your opinion is very important to us.

The purpose of this survey is to learn about your activities of daily life and any impacts you may experience.

The next screen will tell you more about the study, including any risks and benefits of participating. Please read this page carefully, and, if you still would like to participate, please select the option at the bottom of the next screen indicating that you agree to take this survey.

[Next screen]

[Insert ICD]

AGREEMENT TO PARTICIPATE

This consent document contains important information to help you decide if you want to be in this study. If you have any questions that are not answered in this consent document, please contact the Principal Investigator.

I have read and understand the above information. I hereby voluntarily consent and offer to take part in this study and give permission to use the information I provide to take part in the study.

Check one box:

[Print a copy of this consent to keep for your records.](#)

- I have read the above statement, and I agree to participate in this study.
- I have read the above statement, and I do not agree to participate in this study. **[If selected, show: You've indicated that you do not agree to participate in this study. Is that correct? Yes/No. If YES, END SURVEY]**

[Next screen]

INTRODUCTION

Thank you for agreeing to participate in this survey. Before you begin, please note that the survey will take about 10 minutes to complete. If you need to leave the survey part-way through, you can re-enter the survey at the point where you left off using the survey link.

If you have any questions about the study or the survey, or if you need technical assistance, please call:

[Insert number] (Monday-Friday, **[Insert available times]**).

We recommend writing this number down or printing this page before you begin the survey.

Your responses will be kept strictly confidential, and we ask you to be as honest as possible when answering the questions. We are very interested in your opinions. There are no right or wrong answers. The survey will begin on the next screen.

[Next screen]

Section I. Activities of Daily Life

The following set of questions asks you about a variety of difficulties that you may or may not experience in your daily life.

[For questions 1-8, please insert a follow up question (unless specified differently in the comments) for each checked response, except “other” and “I don’t experience...”: “On a scale of 0-10, with 0 being not at all bothersome and 10 being extremely bothersome, how bothersome is this issue for you? [Insert 0-10 NRS scale] AND “How often do you experience this issue? All the time/7 days a week / Most of the time/5-6 days a week / Some of the time/3-4 days a week / A little of the time/1-2 days a week / Rarely/Less than once a week

1. Do you experience any of the following challenges in your **every-day life**? Please select all that apply.
 - Difficulty finishing tasks
 - Difficulty with reading
 - Difficulty with writing
 - Difficulty with school work
 - Difficulty being productive at work
 - Difficulty communicating with others
 - Difficulty having relationships with others
 - Difficulty responding appropriately in social situations
 - Difficulty in social gatherings
 - Difficulty caring for children or handling parental responsibilities
 - A lack of motivation
 - Anxiety
 - Feeling held back
 - Feeling overwhelmed
 - Stress
 - Difficulty being organized at work
 - Difficulty being organized in my daily life
 - Forgetfulness
 - Poor long-term memory
 - Poor short-term memory
 - Other
 - I don’t experience any challenges in my every-day life

[Next screen]

2. Do you experience any of the following impacts on your **life at home**? Please select all that apply.
- Difficulty paying bills on time
 - Difficulty completing a task
 - Difficulty keeping clean and organized
 - Difficulty managing household chores
 - Difficulty caring for children or handling parental responsibilities
 - Difficulty caring for pets
 - Difficulty sleeping at night
 - Other
 - I don't experience any difficulties at home

[Next screen]

3. **Are you unable to do, or have difficulty doing**, any of the following activities? Please select all that apply.
- Reading
 - School work
 - Writing
 - Social activities
 - Driving
 - Holding conversations
 - Tasks requiring attention to detail
 - Attending school
 - Sitting for an extended period of time
 - Hobbies
 - Work tasks
 - Organizing paperwork
 - Prioritizing tasks
 - Managing your emotional responses or mood
 - Other

- I don't have any tasks that are more difficult to do or that I am unable to do

[Next screen]

4. From the list below, are there any activities that you **would like to do that you don't do or avoid doing**? Please select all that apply.

- Attending school
- Reading
- Being part of a social club or organization
- Making plans
- Tasks requiring attention to details
- Tasks requiring sitting still for an extended period
- Social activities
- Playing sports
- Attending sporting events
- House chores
- Sleeping
- Traveling
- Becoming a parent
- Participating in activities with my children
- Getting married
- Other
- I don't avoid any activities

[Next screen]

5. Do you experience any of the following impacts on your **social life**? Please select all that apply.

- Difficulty holding conversations
- I don't feel very social
- I feel awkward
- I tend to forget names
- I am more reserved
- I have difficulty making friends

- I have difficulty maintaining friendships
- I can't sit through a movie
- I forget to call friends
- I am late to events
- I have difficulty focusing when with friends or family
- Other
- I do not experience any impacts on my social life.

[Next screen]

[Ask Q6 only to those who have indicated that they are currently attending school in SQ5]

6. **At school**, do you experience any of the following? Please select all that apply.

- I have difficulty focusing in class
- I have difficulty focusing while doing school work
- I have difficulty taking notes in class
- I have difficulty prioritizing tasks
- I get poor grades
- I have trouble taking tests within the allotted time
- It takes me a long time to complete required tasks
- I have difficulty being on time to class
- Other
- I don't have any difficulties at school

[Next screen]

[Ask Q7 only to those who have indicated that they are employed in SQ7]

7. Related to **work**, do you have difficulty with any of the following? Please select all that apply.

- Being organized
- Focusing on tasks
- Forgetting to do simple tasks
- Taking notes in meetings
- Being productive

- Being on time to work
- Getting along with my co-workers
- Getting along with my boss
- Being engaged in meetings
- Completing tasks on time
- Keeping a job
- Communicating with others
- Other
- I don't have any difficulties at work

[Next screen]

8. Do you experience any of the following difficulties in your **relationships with others**? Please select all that apply.
- I have difficulty communicating with others
 - Friends and/or family get frustrated with me
 - I say things without thinking that hurt others or make them mad
 - I irritate my family and/or friends
 - I have trouble maintaining friendships
 - I have difficulty being in a long-term romantic relationship
 - Dating is difficult
 - Meeting new people is difficult
 - I often get into fights with friends and/or family members
 - I have difficulty listening to others
 - I have difficulty in my relationship with my children
 - Other
 - I don't have any relationship difficulties

[Next screen]

9. Do you have days that you feel are more challenging than others?
- Yes **[ask Q9a]**
 - No **[Skip to Q10]**

9a. What are some of the reasons those days are particularly challenging? Please select all that apply

- I am under a lot of stress
- I am trying to do too much
- I am bored
- I can't get everything done that I want to get done
- I feel rushed
- I haven't gotten enough sleep
- I'm feeling overwhelmed
- I have deadlines to meet
- I'm having an extra hard time focusing
- Other

[Next screen]

10. What **times of the day** are **most challenging** for you? Please select all that apply.

- Early morning
- Mid-morning
- Mid-day
- Afternoon
- Evening

[Next screen]

11. During a typical week, what activities do you usually do **in the evenings (after 5 pm)**? Please select all that apply.

- I work
- I attend classes
- I do homework
- I care for my children
- I help my children with their homework
- I make dinner
- I get my children ready for bed
- I spend time with friends and family at home
- I go out with friends/family
- I exercise
- I do recreational activities/hobbies
- I manage household responsibilities (for example, paying bills, running errands, doing chores, etc...)

- I relax at home
- Other

[Next screen]

12. Do you have difficulty sleeping?

[All options are exclusive choice]

- Every night (100% of the time)
- r Almost every night (75%-99% of the time)
- r Most nights (50-74% of the time)
- r Some nights (25%-49% of the time)
- r Occasionally (Less than 25% of the time)
- r Never

[Next screen]

Section II: More Questions about You

And now we have a few more questions we would like to ask about you.

[Next screen]

13. Are you Hispanic or Latino?

- Yes
- No

14. Which of the following best describes your racial background?

[All options are exclusive choice]

- White (Origins in Europe, Middle East, North Africa)
- Black/African American (Origins in Black racial groups of Africa)
- Asian (Origins in Far East, Southeast Asia, Indian subcontinent)
- American Indian/Alaska Native (Origins in original peoples of North America who maintain tribal affiliations)

- Native Hawaiian/Other Pacific Islander (Origins in Hawaii, Guam, Samoa or other Pacific Islands)
- Multiracial
- Prefer not to answer

[Next screen]

15. How many other people currently live with you at least 50% of the time?

_____ people **[insert drop down]**

[Next screen]

16. How many children, for whom you provide care, currently live with you at least 50% of the time?

_____ children **[insert drop down]**

[Next screen]

17. Please select the option below which best describes your current relationship status:

[All options are exclusive choice]

- Married
- Separated
- Divorced
- Widowed
- Living with partner
- In a serious relationship
- Single, not in a serious relationship
- Other

[Next screen]

18. Which of the following best describes your current annual household income?

[All options are exclusive choice]

- Less than \$24,999
- \$25,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$124,999
- \$125,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 or more
- Prefer not to answer

[Next screen]

19. What type of health insurance do you currently have?

- Medicare or Medicaid
- A plan through a Health Insurance Exchange (Also referred to as Affordable Care Act/ObamaCare)
- Health Maintenance Organization (HMO)
- Preferred Provider Organization (PPO)
- Point-of-Service Plan (POS)
- Tricare (for members of the US military and their families)
- Health care through the Veterans Administration (VA) (for US military veterans)
- CHAMPVA (benefits for families of US military veterans)
- Other
- I don't have health insurance
- Don't know

[Next screen]

20. Do you have a **current physician's diagnosis** of any of the following conditions?
Please select all that apply.

- Aggression
- Alcohol Abuse
- Anxiety
- Asperger Syndrome
- Autism
- Bipolar Disorder
- Cerebral Palsy
- Conduct Disorder
- Depression
- Substance/Drug Abuse
- Eating Disorder
- Epilepsy
- Learning Disability (Tested to have an IQ less than 70)
- Learning Difficulties (for example, dyslexia)
- Motor-Coordination Disorder
- Obsessive Compulsive Disorder
- Oppositional Defiant Disorder (ODD)
- Schizophrenia
- Schizoaffective Disorder
- Sleep Disorder (such as insomnia)
- Speech/Language Disorder
- Tourette's Syndrome
- None of the above **[Exclusive Choice]**

[Next screen]

21. How would you rate your current health overall?

- Excellent
- Very good
- Good
- Fair
- Poor